# Iowa Autism Council Meeting January 11, 2012 Meeting notes taken by Toni Merfeld and Beth Buehler-Sapp

Present: Josh Cobbs, Danielle Sharpe, Marty Ikeda, Jeff Gitchel, Rachel Heiss, Susan Smith, Lin Nibbelink, Jeanne Prickett, Toni Merfeld, Karn Johansen, Barb Stineman, Patrick (Casey) Westhoff, Becky Harker, Ruth Allison, Jim Mumford, Becky Harker, and Beth Buehler-Sapp.

Absent: Sue Baker, Katherine Byers, Steve Muller, Robin Sampson, Debra Waldron, and Charles Wadle.

### **Education Subcommittee Report:**

Marty went over the report the department compiled on Students with Autism in Iowa. "Students with Autism in Iowa: Who are the students, How are Students Served in School, and What is their Achievement? Within this report there was a number of 1,852 students in Iowa with Autism identified as a Primary, Secondary, or Tertiary Disability. (see data below)

The number of students found in each sort was:

Keyword	Number of Students Found
Schedule	4426
Sensory	2594
Structure	1948
Autism as Primary, Secondary, Tertiary Disability	1852
Autism written somewhere on the IEP	1678
Boardmaker	385
PECS	302
TEACCH	120
ABA	46

Duplicates were deleted so that each student appeared in the data file only one time. Incidence by Grade appeared to be 1 in 70 at the Prekindergarten level. The total number of students by grade level for whom services were studied was 1953.

The range of services available was as follows: (see data below)

Each keyword was coded for "likelihood the keyword represents Autism."

Keyword	Code for Keyword
Autism as Primary, Secondary, Tertiary Disability	1
Autism written somewhere on the IEP	1
TEACCH	2
ABA	3
Schedule	4
Sensory	4

The range of services available was (full descriptions from the Information Management System are included at the conclusion of the report): (see data below)

Service	N	Percent of Total
Speech	929	48%
Specialized Transportation	859	44%
Paraprofessional (Medicaid)	666	34%
Paraprofessional (Non-Medicaid)	383	20%
Assistive Technology	240	12%
Occupational Therapy	227	12%
Nursing	153	8%
Health	132	7%
Autism Resource	80	5%
Specialty Services	30	1.5%
Other Medicaid Eligible	26	1%
Specially Designed Instruction	20	1%
Adaptive PE	6	<1%
Audiology	6	<1%
Consultation	12	<1%
Itinerant Teacher of Deaf	Small N (<5)	<1%
Counseling	8	<1%
Hospital/Homebound	Small N (<5)	<1%
Interpreter	Small N (<5)	<1%
Orientation and Mobility	Small N (<5)	<1%
Physical Therapy	10	<1%
Psychological Services	Small N (<5)	<1%
Social Work	18	<1%
Transition	Small N (<5)	<1%
Itinerant Teacher of Blind	Small N (<5)	<1%
Home Intervention	0	0%
Service Coordination (0-2)	15	9% of PreK, number of children
		0-2 not known for this analysis
Developmental Service (0-2 only)	11	6% of Pre K, number of children
		0-2 not known for this analysis
Other Outcome Linked Service (0-2)	Small N (<5)	<1% of Pre K, number of children
		0-2 not known for this analysis
Work Experience	37	8% (469 students Grades 10-12)

There are no data at the state level for comparison purposes, nor are there benchmarks
Nationally for what kinds of services ought to be prevalent for what percentage of students.
For students with Autism, it would be reasonable to expect services in the areas of communication, behavior, and social interactions. However, it would also be reasonable for service decisions to be made at the IEP team level. There is also no way to easily capture services in the behavior or social areas.

If this data is tracked again next year this will help us to see the changes in increases, decreases, etc. For those students exiting the use IEP services this is mostly due to students graduating or dropping out.

It is important to realize that this report is only reflective of students with IEP's and doesn't include those students with 504 plans or learning disabilities.

Dr. Jeanne Prickett stated "It's about raising expectations and providing services to close the achievement gap rather than to track students."

Some districts have an ART (Autism Resource Team) which can assist the IEP Team in setting up students IEP's when needed.

## **Student Demographics**

Grade	Count	Percent of	Count for All	Incidence by
		<b>Autism Count</b>	Students	Grade
PK	397	13%	27208	1 in 70
K	191	6%	39321	1 in 250
1	239	8%	35391	1 in 150
2	228	7%	35139	1 in 150
3	234	8%	34950	1 in 150
4	221	7%	35098	1 in 160
5	246	8%	35347	1 in 140
6	201	6%	35094	1 in 170
7	192	6%	35429	1 in 200
8	175	6%	35274	1 in 200
9	192	6%	37014	1 in 200
10	161	5%	36614	1 in 230
11	149	5%	36474	1 in 240
12	276	9%	37544	1 in 130
Total	3102		468,689	1 in 150

#### Services

Because of the method used to aggregate the data, information on all services being provided to students was available on 1953 students of the 3102 students (95% confident that the population results are +/- 1 point from the results presented).

The number of students by grade level for whom services were studied was:

Grade	Number	Percent of Total
PK	162	8%
K	63	3%
1	150	8%
2	136	7%
3	143	7%
4	139	7%
5	154	8%
6	132	7%
7	128	7%
8	129	7%
9	148	8%
10	123	6%
11	120	6%

12	226	12%
Grand Total	1953	

The question was asked, "How many IEP goals have progress monitoring in them?"

IEP's are written to commit to services needed by a student but if and how progress monitoring is part of this probably varies since we're talking about many districts within this process.

It's also important to know that no LRE (Least Restrictive Environment) information is included in this report data. Thus would tell us what amount of time a day a student spends in specific environment such as general education versus special education.

Dr. Jeanne Prickett said that there is a correlation between "Cost versus the amount of time spent in an activity or environment."

Marty said that in the next report there could be a proficiency by LRE table included.

Becky Harker stated that she would like to see this expanded to include all kids with intellectual disabilities and not just those with IEPs.

Marty agreed that this would be nice and stated, "It would be nice to do this and that, "He would like for there to be a mandated test on all kids with disabilities with Metric results to assess."

Becky said, "If I were a parent of a child with a disability I would be supportive of this."

The report indicates that 65% of kids with disabilities made growth last year. The questions that evolve from this fact are as follows:

How rigorous were the services provided to achieve this outcome? How much growth was achieved?

These specifics were not included which need to be included in future reports in order to validate that data.

With this 1 in 70 kids represented in the report it is highly likely they would be considered to be a child on the spectrum. (see data available in table on previous page)

Marty said we know what proficiency levels kids have to meet to meet achievement after high requirements.

Karn Johansen asked about the descriptor listed as nursing in the report. The council members as a consensus thought that this most likely refers to medication administration to students while in school.

Dr. Jeanne Prickett stated, "This is a really enormous job to do with data and it's really appreciated." It's very labor intensive and time consuming. The group consensus was Kudos to the Department of Education and the staff involved in this process for their work.

## **Adult & Adolescent Services subcommittee report:**

I-Part received refunding for 6 months to fund their programming through June 2012. As of July 1, 2012 they will have to receive additional funding or cease operations. Susan Smith spoke briefly about their services and the fact that they have gone into multiple types of facilities to doing training for service providers. This includes families, Intermediate Care Facilities, Mental Health Facilities, Skilled Nursing Facilities, and individuals transitioning from Out of State back to Iowa. In helping families, this has decreased the number of individuals needing to enter into residential facilities in Iowa. Their goal is to get individuals back to more independent or home-based living.

Casey Westhoff spoke briefly about the Department of Human Services Community Reinvestment Plan. This requires an Axis 1 diagnosis of Mental Illness or Intellectual Disability in order for a person to receive waiver services.

Casey also stated that competent and well trained direct support staff does make a difference. Providers aren't allowed to pay people for what they should be getting.

Ruth Allison wanted to talk about transition planning services available for students now and in the coming years. Voc Rehab is doing some development of programs called TAP (transition alliance planning) throughout the state as follows:

Sioux City Council Bluffs Ankeny Urbandale Des Moines Storm Lake Spencer Fort Dodge Cedar Rapids (2013)

These programs have counselors and programs for students available at each of these districts. Each of the AEAs has an ART (Autism Resource Team) that Voc Rehab can connect with.

Josh said that parents want to talk transition but that more platforms need to be designed for this.

Casey asked Josh, "Can we get the data for adults as comparative to what we got regarding school aged persons?"

Lin Nibbelink for the Department of Human Services says this is going to be difficult for 2 reasons.

- 1. Time would be needed to parse out data by staff.
- 2. Confidentiality sharing a person's information.

Most council members feel that historically now may be a better time than ever before to have a chance of working with the administration at DHS than with previous administrations.

Casey suggests a random request for information not tied to identification of individuals, i.e., "We have 3100 kids; if we give you their names & birthdates can you tell us non-identifiably what services are being provided?"

Ruth Allison says that by 2013 the data that Voc Rehab is collecting should be available to tell us some of these things.

Becky Harker hopes the future message to the education system is "We're counting on you to do your job well enough that these individuals won't be entering the adult system."

## **Financing of Care subcommittee report:**

- 1. Support amending Hawk-I to include behavioral disabilities.
- 2. Expand Coverage.
- 3. More specific look at eligibility scores. Example; IQ score of 0-90 to be eligible yet as person with a score of 91 may be no more eligible than the person with the score if 90 with 90 being eligible and 91 being ineligible.
- 4. ASD's may all go under the Autism umbrella, DSM 5.

Rachel Heiss doesn't think this is a good idea in terms of persons provided for by waivers. You need a piece that addresses the functional assessment just as with #3 above.

- 5. Services are county controlled and we hope this will change to provide more eligibility for more individuals.
- 6. Should offer options on the continuum of services/eligibility.

Karn Johansen questioned whether they will possibly include PDD-NOS and Asperger's within the current Autism services waiver. Rachel Heiss said this is unlikely due to the fact that there are already other waivers with long waiting lists and duplications would create problems. Karn says many PD-NOS diagnosed youths are going to Four Oaks because they can't get waiver services to serve them in their home. They can't get on the SED waiver because their primary disability is PDD-NOS.

Casey Westhoff said "It is the interest of DHS to expand services to persons under the waivers but that even to bring the current system even, it will cost the state \$142 million so it is unlikely that additional services will be eligible in the immediate future.

Rachel Heiss suggests they expand other waiver services eligibility rather than having everyone on the MR waiver. There are many people under the umbrella, but the system needs to look at services more by individual need.

Josh says new waivers are not being created because there are no new "buckets of money."

Jeff Gitchel says he tries to keep pushing for educational waivers for persons with disabilities but doesn't hear much back.

Josh wanted to tell everyone that February 13<sup>th</sup> is "A Day on the Hill" an Autism Awareness Day at the Capitol. Josh was looking for a volunteer to represent the council and Casey Westhoff volunteered to do so.

MHDS Redesign: The MHDS Redesign evolved last year with the creation of the following workgroups:

IDDD, Judicial, Regionalization, Children's Brain Injury, Mental Health, & PMIC

Recommendations developed from their efforts are as follows: For example under Regionalization; Blackhawk and 7 other counties agreed to form a region for services eligibility. A Regionalization requires 3 or more counties which are contiguous to each other to form and a population of no less than 200,000 residents and no more than 700,000. Director Palmer is a supporter of Regionalization as well as is DHS. However, DHS Director, with the approval of the MH/DS Commission, may grant a waiver if the requirements are not workable.

Funds needed to represent some of the proposed initiatives are not within the Governor's current budget. This year's already approved reorganization will cost \$142 million.

Casey Westhoff stated that "When you intertwine property taxes within a system this creates a large problem." When following Olmstead Principles this will be a recurring theme. There is more flexibility if using various assessment tools in regards to diagnosis and eligibility for waivers. This year there has been more openness to advocacy groups input.

Council members ask, "Who is responsible for monitoring the county based systems now?" And "Who will be responsible for monitoring the regionalized system?"

There needs to be a functional assessment to provide some supports to families in need? For instance, there may be parents, who have a child with an age of 19 and an IQ score of 76, and 75 or under may be the cutoff for eligibility but with no functional assessment this may be irrelevant to the abilities of the individual.

Respite care and community based programs are sometimes a families only option but not an option if a waiver is not available to pay for services. Josh says people often see dollars and not the people involved. Jeff Gitchel mentioned that in a recent survey he saw that many participants said "Money spent on respite care was more beneficial than money spent on services."

Discussion regarding Dr. Waldron's Children's Mental Health subcommittee's report (Dr. Waldron was absent).

There are a large number of kids from Iowa receiving residential services out of state. This often happens because no in-state facility will take these kids. It was suggested that the use of a SIS Support Intensity Scale is most helpful when determining if a facility can meet a person's needs. More use of this assessment scale by providers would likely keep more kids closer to home. Three large facilities nationwide that take in all type of applicants for placement are in the following areas: Tulsa, Oklahoma/Carbondale, Illinois/and Devereaux/Florida. Statistics show more than 100 Iowa kids in out of state placement with some of them lucky enough to be in border towns somewhat close to families.

Jeanne Prickett feels that looking at the expanded core curriculum is an important factor.

How to get an interpreter?

How to make a visual-relay phone call?

How to use an interpreter to go to the doctor, etc.

She strongly urges this council to have an expanded core curriculum be a required part of assessment criteria for residential facility placement.

With the current Mental Health Redesign for juvenile's they are looking at the aspects of More Psychiatrists, Geographical Services, and Use of a Telehealth System. As part of this trend Rachel Heiss says money spent in post-doctoral programs has been more efficient than trying to influence psychiatrist's geographical selections. The vast numbers of counties have no psychiatrists/psychologists.

**Additional recommendations**: Josh nominated Casey to draft an addendum letter of recommendations as concurred upon by the council in regards to the following items: In 2 weeks, Casey Westhoff will have the draft recommendations letter ready.

Exploration of functional disabilities 2012 before affordable healthcare is in place. HCBS Waiver System

**Website Committee**: Due to Sue Baker's absence with her as chair of the Website committee a consensus was reached to have a conference call sometime before the April 11 to focus on the content recommendations. Josh will send out a list of website committee members so council members can contact with their input. For the April 11<sup>th</sup> meeting Marty will have data packages available.

**Miscellaneous:** Monday, February 13<sup>th</sup> is advocacy Day on the Hill at the Capitol. Thursday night, February 16<sup>th</sup> there is a session in Sioux City and Friday, December 17<sup>th</sup> there are 2 sessions in Des Moines and 1 in Iowa City.

Casey Westhoff states "There are 425 disabled students to graduate in the next 2 years" and "How do we find out where they're going without the ability to track with data.?"

This is based on the 425 that Voc Rehab can tell us about and it would be great to know the following: What services are needed?

Is the student going onto further schooling/programming?

Indicator 14, Department of Education data may be helpful with this.

Jeff Gitchel made a motion to adjourn the meeting and Josh Cobbs seconded the motion.